



## EURORDIS-Rare Diseases Europe Answer to European Commission Consultation “Have your say on reinforcing Social Europe”

### About EURORDIS

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 900 rare disease patient organisations from more than 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. More information available at <http://www.eurordis.org/>.

### About the European Commission Consultation “Have your say on reinforcing Social Europe”

The European Pillar of Social Rights (Social Pillar) was proclaimed in November 2017 by the European Parliament, the Council of the European Union and the European Commission. It is the first set of social rights proclaimed by EU institutions since the Charter of Fundamental Rights in the year 2000. The Social Pillar sets out 20 key principles and rights to support its 3 overarching goals: equal opportunities and access to the labour market, fair working conditions, and social protection and inclusion.

While some policy actions at EU and national level have been put in place towards the achievement of the rights set by the Social Pillar, this has been done in a rather ad-hoc way without a concrete plan to fully implement all 20 principles. To remedy this, the European Commission will propose an Action Plan on the European Pillar of Social Rights in the beginning of 2021 ([letter of intent of State of the Union 2020](#)). Social partners are invited to reply to this [consultation](#) as part of the process towards this Action Plan.

### EURORDIS response to the European Commission Consultation

EURORDIS, through this contribution, submits new policy action or legal initiatives needed on EU and national levels based on its most recent position paper '[Achieving Holistic Person-Centred Care to Leave No One Behind](#)', its [reply to the initial EC consultation on the Social Pillar in 2016](#), and in consultation with the [EURORDIS Social Policy Action Group \(SPAG\)](#), composed of representatives of persons with a rare disease (RD) from across Europe.

The recommendations proposed in this contribution are accompanied by a synthesis of the specific challenges and needs of the particularly vulnerable community of people living with a rare disease.

In addition, EURORDIS supports the contributions to the consultation released by the Social Platform and the European Disability Forum (EDF), organisations of which EURORDIS is a member.

## A social Europe for people living with a rare disease

Today, the **30 million people living with a rare disease (PLWRD) in Europe and their family members (often the main carers) remain a marginalised, vulnerable and largely invisible population**, with little information about their diseases and their rights, few treatments, and a high level of psychological, social and economic vulnerability.

**It is urgent to address the serious unmet needs of PLWRD and their families. Doing so requires a multi-sector approach** from research, to diagnosis, access to treatment, health care and social care, and long-term care, at both national and European levels. The evidence of recent surveys to PLWRD demonstrates how serious and urgent these unmet needs have become in the last years and how they have been exacerbated by the COVID-19 pandemic.

Important frameworks have been put in place to support rare disease care and these must be sustained, but alone, they will not suffice. **More action is required by all stakeholders to ensure that European Union (EU) Member States (MS) effectively develop and implement policies and services that guarantee holistic, long-term care and the respect of social rights for PLWRD.** These actions must be fully integrated within a comprehensive EU-wide action plan with clear targets and outcomes.

The European Pillar of Social Rights is paving the way for the EU and its MS to deliver more effective social rights, equal opportunities and social inclusion for all, including PLWRD. Therefore, EURORDIS welcomes the European Commission's proposal to develop an Action Plan for the delivery of the European Pillar of Social Rights and wishes to highlight through its recommendations in this answer to the consultation, how **addressing the social issues faced by PLWRD directly contributes to making several of the 20 principles within the European Pillar of Social Rights a reality.**

Before delineating actions linked to the delivery of several of the Pillar's principles in the section below, EURORDIS wishes to highlight that significant improvements can be achieved if the following cross-cutting premises are enshrined within the Action Plan:

- Care and support are organised within a **holistic, person-centred, multidisciplinary, continuous and participative approach**, considering both PLWRD and the carers.
- Care providers across sectors are equipped with **knowledge, good practice and care coordination strategies**, allowing them to take into account the specificities of rare diseases.
- **Integrated, long-term care is delivered in an effective and timely manner**, in coordination within and between health, social and community services and organisations representing patients like PLWRD.
- Mechanisms are established to **meaningfully engage PLWRD and their representative organisations in the design, implementation and monitoring of policies and services**;
- Social and disability policies effectively take into account the **specificities of complex conditions and disabilities, such as rare diseases.**
- PLWRD and their families are **informed and empowered to understand and manage their condition.**

In the following section, we will detail the policy action or legal initiatives needed to address the needs of PLWRD that will contribute to the implementation of a number of principles within the European Pillar of Social Rights.

## I. Equal opportunities and access to the labour market

**Principle 3: Equal opportunities:** *This principle outlines the right of everyone to equal treatment and opportunities regarding employment, social protection, education, and access to goods and services available to the public.*

### Policy actions needed

- All EU and national level legislation must guarantee that there is no form of discrimination **based on health or disability status. The Horizontal Equal Treatment Directive should be swiftly adopted and any discrimination on all grounds** covered in the Article 21 of the European Charter of Fundamental Rights, and in all fields, **should be tackled.**
- All legislative proposals and recommendations deriving from the European Pillar of Social Rights must **take into account the specific needs of PLWRD, their carers and others with complex diseases/disabilities.**
- The 'Social Scoreboard' should introduce **clear indicators** that reflect the reality on the ground and monitoring tools to support effective policy changes.
- Financial and structural support should be allocated to **ensure the sustainability of Europe-wide platforms such as the [European Reference Networks](#), the European Network of Resource Centres for Rare Diseases and [Orphanet](#).** These platforms gather and share essential knowledge and good practices that support MS to effectively address both the health and the social needs of PLWRD. An **enabling environment should thus be created to integrate these initiatives within national health and welfare systems.**

### The situation for people living with a rare disease

Evidence from the first European survey on the everyday impact of rare diseases<sup>1</sup> revealed that for **85% of the respondents the rare disease impacts upon several aspects of their health and everyday life.** The survey demonstrates that the consequences of rare diseases extend to the [Activities of Daily Living](#) (ADLs), socio-economic, family, education, employment and other social inclusion spheres. For many, if not most PLWRD and their carers, plights like poverty, unemployment, stigmatisation and social exclusion are a daily reality, and a direct consequence of their medical condition.

**Principle 4. Active support to employment:** *This principle outlines the everyone's right to timely and tailor-made assistance to improve employment or self-employment prospects. This includes the right to receive support for job search, training and re-qualification. Everyone has the right to transfer social protection and training entitlements during professional transitions (...).*

### Policy actions needed

- Access to **high quality education must be guaranteed to all PLWRD and with complex conditions.** When necessary, adapted schooling should be accessible and delivered in a way that supports all individuals to reach their maximum potential and to be prepared to access employment.

<sup>1</sup> Survey of 3000 PLWRD and carers, conducted through the EURORDIS survey initiative Rare Barometer Voices <https://www.eurordis.org/voices>, within the EU-funded project INNOVCare [www.innovcare.eu](http://www.innovcare.eu) Results available here: <http://bit.ly/SurveyRD>.

- **Tailor-made assistance to improve PLWRD's employment or self-employment**, such as career counselling to explore fulfilling professional avenues, is needed.
- All EU and national level legislation must guarantee that there is **no form of discrimination based on health or disability status, concerning all forms of employment**, including recruitment, hiring, employment, career advancement and safe and healthy working conditions. The **Employment Equality Directive must be fully implemented with targeted support via EU funds, appropriate legislative frameworks**, and exchange of practices to support the labour market integration of groups in disadvantaged situations as part of active labour market policies.
- Access to **social protection measures, pension rights and care support** must be guaranteed for PLWRD, their carers and others with complex conditions when leaving the labour market or having to work part-time due to the disease.
- Measures to ensure **PLWRD and with disability who wish to study and/or to be active as volunteers** for civil society organisations, **are in no way deprived from their rights, including disability and retirement benefits**.

## The situation for people living with a rare disease

Despite being eager to work and often having the capacity to do so, today, PLWRD have serious challenges with access, retention and return to employment. This is also the case of their carers who need support to fulfil their caring role whilst remaining in employment.

The European survey showed that **70% of PLWRD had to stop or reduce professional activity**. In addition, those who face unemployment may remain out of the labour market for several years while awaiting a diagnosis or while taking on the role of care coordinator.

Furthermore, having a rare disease **limited the professional choices of 76% of the respondents, while 67% felt that it limited their opportunities to progress in their career**.

## II. Fair working conditions

The recommendations under the following section will also be key for the delivery of **principle 4** on active support to employment, in addition to contributing to **principles 5, 9 and 10** outlined below. With access to the necessary conditions at work, a greater number of PLWRD will be able to access and remain in the labour market.

**Principle 5: Secure and adaptable employment:** *Regardless of the type and duration of the employment relationship, workers have the right to fair and equal treatment regarding working conditions, access to social protection and training. (...). In accordance with legislation and collective agreements, the necessary flexibility for employers to adapt swiftly to changes in the economic context shall be ensured. Innovative forms of work that ensure quality working conditions shall be fostered. (...).*

**Principle 9: Work-life balance:** *Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities (...).*

**Principle 10: Healthy, safe and well-adapted work environment and data protection:** *Workers have the right to a working environment adapted to their professional needs and which enables them to prolong their participation in the labour market (...).*

### Policy actions needed

- European countries, via the implementation of the Work-Life Balance Directive and other means, must **ensure that people with complex conditions/disabilities and their carers have the right to** specific mechanisms that support their access and retention in the labour market:
  - **Flexible work arrangements**, such as flexible working hours and remote work;
  - **Reasonable leave of absence** due to their health/disability condition or caring responsibilities;
  - **Reasonable accommodation** in the workplace.
- The European Commission should provide MS with the necessary **support to ensure the full implementation of Directive (EU) 2019/1158 on work-life balance** for all parents and carers of PLWRD who need those provisions.
- The European Commission should provide **guidelines for MS on how to ensure reasonable accommodation for PLWRD in the workplace**, in line with Article 5 of Directive 2000/78/EC. The guidelines should encourage MS to entitle PLWRD with adequate leave of absence and flexible work arrangements, in line with the provisions offered to parents and carers within the Directive (EU) 2019/1158 on work-life balance.

### The situation for people living with a rare disease

As described under principle 4, PLWRD face serious challenges with access, retention and return to employment, linked to the time they need for care activities and the limited prospects in the advancement of their careers. For instance, **58% of survey respondents were absent from work 15 days in the year prior to the survey**. This brings about devastating socio-economic consequences. In fact, **69% of respondents suffered a decrease in income due to their disease**.

## III. Social protection and inclusion

**Principle 11: Childcare and support to children:** *Children have the right to affordable early childhood education and care of good quality. Children have the right to protection from poverty. Children from disadvantaged backgrounds have the right to specific measures to enhance equal opportunities.*

### Policy actions needed

- The future **EU Child Guarantee must fully integrate the challenges of children** in most vulnerable situations, as in the case of children **living with a rare disease, guiding EU and national policy frameworks and financial resources to ensure adequate resources for childcare and early intervention services**.

### The situation for people living with a rare disease

70% of genetic rare diseases start in childhood, with children thus being a significant portion of PLWRD. With their families, they **face fragmented care pathways and mainstream services that are not flexible enough** to take into consideration their unprecedented needs. As a consequence, obtaining the correct diagnosis, child-care/education, and support to manage the transitions between hospital and home and between childhood and adulthood remains a challenge.

**24% of the survey respondents with school-age children declared that the schooling provided for their child was badly adapted**. Additionally, **46% declared that their children were absent from school over 20 days per year due to their disease and care pathway**.

**Principle 12: Social protection:** *Regardless of the type and duration of their employment relationship, workers, and, under comparable conditions, the self-employed, have the right to adequate social protection.*

### Policy actions needed

- EU MS must guarantee that all PLWRD and their carers are **entitled to access a social worker and adequate social protection and social inclusion provisions**, adapted to their individual needs and to the cost of living.

### The situation for people living with a rare disease

PLWRD who responded to the Europe-wide survey stated **serious unmet needs regarding the access to a range of social and (re)habilitation services**. For example: **50% had uncovered needs on accessing disability benefits; 48% had insufficient or no access to rehabilitation services; 40% needed further assistance for house chores and daily tasks; 21% had uncovered needs in regards to day care services; and 21% had insufficient or no access to personal assistant services.**

Access to the various social and support services and benefits may be hindered by the fact that **one third of PLWRD have insufficient access to a social worker**: 22% of the respondents do not have access to a social worker and would need it, while 8% have access, but it is not enough to cover their needs.

**Principle 16: Health care:** *Everyone has the right to timely access to affordable, preventive and curative health care of good quality.*

**Principle 18: Long-term care:** *Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.*

### Policy actions needed

- EU MS must **safeguard equity in national UHC strategies and essential health service packages**, ensuring that these address the health needs of their most vulnerable populations, such as PLWRD.
- EU MS must implement **specific mechanisms to guarantee coordination between national policy sectors within a multidisciplinary approach**, engaging health, social, work, education and research Ministries. Inter-Ministerial working groups and shared budgets between Ministries should be implemented.
- EU MS must **promote coordination and interoperability between all parties involved in the care provision**. Coordination protocols, procedures, IT and e-health tools can be used for this purpose; **Training for health and social service providers** must be developed and delivered.
- European Reference Networks and their constituent health care providers must be supported for their continued **function as a platform to collect and disseminate data, good practices and guidance on health care and integrated care for rare diseases**, in cooperation with organisations representing PLWRD.
- **Case management, as an effective care coordination mechanism, should be implemented across EU MS to support integrated and long-term care** for PLWRD, their carers and others with complex diseases/disabilities. Training on case management for rare diseases should be developed and the case manager profession should be recognised within the national codes of occupations.



- **EU MS must ensure their health systems are more resilient during situations of crisis and pandemics to avoid the exacerbation of vulnerabilities of people living with rare and chronic diseases. This includes the need to safeguard the continuity of care by directing funds and efforts towards to reinforce medical workforce and equipment; adopting concrete measures/protocols for the provision of emergency healthcare for those with rare and serious conditions; and facilitating virtual health care and the administration of certain therapies at home.**

## The situation for people living with a rare disease

**PLWRD need follow-up care and support from different categories of health professionals, often from several different medical specialities, as well as from social workers and other social and local service providers.** These may also include (re)habilitation, day-care, home care, personal assistants, respite services, adapted schools and work places, psychological support and social prescribing, among others. Therefore, PLWRD need a holistic care approach.

However, PLWRD face fragmented care pathways and mainstream services that are not flexible enough to take into consideration unprecedented needs. As a consequence, obtaining the correct diagnosis, the needed healthcare, social care, child-care/education, and support to manage the transitions between hospital and home and between childhood and adulthood remains a challenge.

The European survey revealed that 65% of PLWRD have to visit different health, social and local services in a short period of time and **67% feel that these services communicate badly between each other.** In addition, 7 in 10 find that organising care is time-consuming and **6 in 10 find it hard to manage.**

**Evidence also demonstrates that the challenges of PLWRD have been multiplied during the COVID-19 pandemic, with access to care, employment, inclusion in society and mental health being severely impacted.** According to a survey<sup>2</sup> conducted during the first wave of the pandemic, **84% of European respondents experienced disruption of their care** due to the COVID-19 crisis. Furthermore, **64% said that they were concerned this would be detrimental to their health** or the health of the person they care for, whereas **3 in 10 reported that this would probably or definitely be life-threatening.**

***Principle 17: Inclusion of people with disabilities:*** *People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.*

## Policy actions needed

- The future **European Strategy on the Rights of Persons with Disabilities must provide guidance to MS on disability assessment procedures to ensure persons with all types of disability, including persons with rare conditions or multiple impairments, are not overlooked and are provided with adequate levels of disability allowance, social protection schemes, community-services and independent living arrangements.**
- **A CRPD Unit should be established within the European Commission, placed in the EU Directorate General for Justice and Consumers, under the supervision of the EU Commissioner for Equality.** This unit would be responsible for the implementation of the UN Convention on the Rights of Persons with Disabilities and for coordinating the work of all disability focal points in EU institutions.

<sup>2</sup> Survey of almost 7000 PLWRD and carers, conducted through the EURORDIS survey initiative Rare Barometer Voices <https://www.eurordis.org/voices>. Results available here: [http://download2.eurordis.org/rbv/covid19survey/COVID19\\_EN.pdf](http://download2.eurordis.org/rbv/covid19survey/COVID19_EN.pdf).

## The situation for people living with a rare disease

A high percentage of PLWRD are affected by motor, sensorineural or intellectual impairments, which can occur simultaneously. **72% of PLWRD involved in the European survey on everyday life, declared having difficulties with motor or sensorial functioning.** According to the same survey, **PLWRD face serious limitations in their Activities of Daily Living (ADLs).**

Recognition of their disability is a main challenge for PLWRD: **34% of the respondents who have been submitted to a disability assessment find the percentage of disability assigned to them too low,** and **19% have not been submitted to a disability assessment despite feeling that they need to.**

The challenge of obtaining a disability assessment affects timely access to tailored support and services. PLWRD are often prevented from accessing disability benefits. **50% of the survey respondents have uncovered needs regarding the access to disability benefits: 28% of the respondents have access to disability benefits but find that they are not enough to cover their needs;** while 22% do not have access to these benefits but consider that they would need to.